

Comparison of Survival Between Patients Receiving General Ambulatory Palliative Care and Patients Receiving Other Palliative Care - Analysis of Data of a Statutory Health Insurance Data

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Abstract

Background

The care of palliative patients takes place as non-specialized and specialized care, in both ambulatory and stationary settings. However, palliative care is largely provided as non-specialized care in the ambulatory sector (AAPV). This study aimed to investigate whether the survival curves of AAPV patients differed from those of the more intensive palliative care modalities and whether AAPV palliative care was appropriate in terms of timing.

Methods

The study is based on claims data from a large statutory health insurance. The analysis included 4,177 patients who received palliative care starting in 2015 and who were fully insured one year before and one year after palliative care or until death. The probability of survival was observed for 12 months. Patients were classified into group A, which consisted of patients who received palliative care only with AAPV, and group B including patients who received stationary or specialized ambulatory palliative care. Group A was further divided into two subgroups. Patients who received AAPV on only 1 day were assigned to Subgroup A1, and patients who received AAPV on two or more days were assigned to Subgroup A2. The survival analysis was carried out using Kaplan-Meier curves. The median survival times were compared with the log-rank test.

Results

The survival curves differed between groups A and B, except in the first quartile of the survival distribution. The median survival was significantly longer in group A (137 days, n=2,763) than in group B (47 days, n=1,424, $p<0.0001$) and shorter in group A1 (35 days, n=986) than in group A2 (217 days, n=1,767, $p<0.0001$). The survival rate during the 12-month follow-up was higher in group A (42%) than in group B (11%) and lower in group A1 (38%) than in group A2 (44%).

Conclusions

The results of the analysis revealed that patients who received the first palliative care shortly before death suspected insufficient care, especially patients who received AAPV for only 1 day and no further palliative care until death or 12-month follow-up. Palliative care should start as early as necessary and be continuous until the end of life.

Background

Palliative care is a proven approach for patients and their families facing the problems associated with life-threatening illness to improve quality of life [1]. In the German health care system, palliative care is provided at different levels of care and by different healthcare providers. Ambulatory palliative care can be delivered as basic ambulatory palliative care (AAPV), which is provided by general practitioners (GPs)

and ambulatory nursing services. Specialized ambulatory palliative care (SAPV) is delivered by multi-professional specialised palliative care teams (palliative medicine physicians and palliative care nurses). Stationary palliative care is provided in designated hospices, palliative care units in hospitals, or in hospitals without a designated palliative care unit and in nursing homes [2–4].

Mecklenburg-Western Pomerania, Germany's federal state with the lowest population density, is located in the northeastern part of the country at the Baltic Sea. Mecklenburg-Western Pomerania has a high proportion of elderly and a low number of specialized health care providers [5–7]. In rural areas, AAPV by GPs plays a major role. AAPV is an important part of home care for palliative care patients and for early recognition of palliative care needs. In addition to communication and the determination of therapeutic goals, AAPV comprises symptom control and the coordination of treatment, if necessary with the involvement of SAPV teams or stationary palliative care [8–10].

Survival curves show the time period between the start of palliative treatment and death or the date of the last follow-up [11]. A short period of time indicates that palliative care was started shortly before death. In our recent analysis of claims data from a statutory health insurance, we observed that about two-thirds of palliative care patients in Mecklenburg-West Pomerania received only AAPV [12]. This study aimed to explore whether the survival curves of AAPV patients differed from those of the more intense palliative care modalities and to evaluate whether AAPV palliative care was appropriate in terms of the timing.

Methods

Claims Data

The analyses were based on claims data of the AOK Nordost (2015/16), which is a large statutory health insurance provider in the federal states of Berlin, Brandenburg and Mecklenburg-West Pomerania, Germany. The AOK Nordost covers more than a quarter of the total population in the federal state of Mecklenburg-Western Pomerania. The claims dataset included demographic information (age, gender, date of death) as well as stationary and ambulatory diagnoses and treatments. In the data of the ambulatory care service, however, it is not possible to determine whether ambulatory nursing services provided general palliative care since there is no specific reimbursement code for nursing palliative care.

Definition of palliative care

Patients who received at least one palliative care service of the AAPV, SAPV, or palliative care in a hospital or hospice were included in the analysis. The reimbursement codes for palliative initial assessment of the patient's health and care status, including setting up a care plan, and supplementary palliative care in an ambulatory setting were used to determine patients with AAPV healthcare services. Contracts for SAPV-Teams containing the kind of care and delivery dates of the healthcare services were used to determine patients receiving SAPV care services. Operations and procedures codes for complex palliative care treatment by palliative care specialists and multidisciplinary teams on any hospital ward including

intensive care units and complex palliative treatment in specialized palliative care units were used to determine patients with a stationary palliative treatment in a hospital.

Study Population

The study population included 4,177 patients in Mecklenburg-Western Pomerania who started their palliative care in 2015 and were insured 12 months before and 12 months after palliative care. The patients were followed up for a maximum of 12 months after the start of any palliative care. A detailed description of the sample construction was recently published [12]. The survival times of the included patients was observed. Patients who received AAPV palliative care only were categorized into group A. Group B included patients who received also stationary palliative care or SAPV. Group A was further divided into two subgroups. Patients who received AAPV on only 1 day were assigned to Subgroup A1, patients receiving AAPV during two or more days were assigned to Subgroup A2.

Diagnosis

The patient's diagnoses were identified based on the International Statistical Classification of Diseases (ICD) codes (10th revision, German modification). Both All hospital diagnoses (primary and secondary diagnosis codes) and ambulatory diagnoses verified in at least two quarters of a single year (M2Q criterion) were used.

Statistical Analyses

Descriptive statistics are presented as absolute numbers and percentages for categorical variables, and medians and interquartile ranges (IQR) for continuous data. Kaplan-Meier analysis was applied to compare survival times among groups A and B as well as groups A1 and A2. The differences between the curves were analysed with the log-rank test. All statistical analyses were conducted using SAS Software release 9.4 (Version 9.4; SAS Institute, Cary, NC, USA) and a p value of <0.05 was considered statistically significant.

Ethics

The present study is based on a retrospective analysis of anonymised health insurance claims data available for research proposes, and therefore no formal ethics committee approval was needed [13].

Results

A total of 4,177 palliative care patients were included in the study. The median age of the patients was 81.0 years (IQR: 74.0 – 87.0) and 54.6% (n=2,280) were female (Table 1). During the 12-months follow-up period, 68.6% (n=2,866) of patients died, their median survival time was 76 days. Most of the patients (97,3%) had at least one stationary or ambulatory diagnosis. Of these 2,288 patients (56.3%) had a diagnosis of a malignant neoplasm (ICD-10 code: C00-C97). Overall, 85.7% (n=3,579) of the palliative care patients received at least one service including general palliative care, 21.6% (n=904) of the patients received at least one SAPV service. Altogether, 18.9% (n=791) of the patients received stationary palliative

care in a hospital at least one time over the period of observation. In total, 2.7% (n=112) of the patients were cared for in a hospice.

Table 1
Characteristics of the palliative care patients in 2015/16, 12-months follow-up

Number of palliative care patients, n	4,177
Age (years), median (IQR)	81.0 (74.0 – 87.0)
Female, n (%)	2,280 (54.6%)
Dead, n (%)	2,866 (68.6%)
- median survival days (95% CI)	76.0 (70.0, 83.0)
Stationary or ambulatory diagnoses, n (%)	4,062 (97,3%)
- oncologic patients, n (%)	2,477 (61.0%)
Number of patients (n, %) with services in	
- AAPV	3,579 (85,7%)
- SAPV	904 (21,6%)
- Hospital	791 (18,9%)
- Hospice	112 (2,7%)
number of care days, median, IQR	
- AAPV	2.0 (1.0 – 4.0)
- SAPV	17.0 (7.0 – 49.0)
- Hospital	14.0 (9.0 – 23.0)
- Hospice	37.5 (20.5 – 70.0)
IQR: interquartile range (25 th quartile – 75 th quartile), CI: confidence interval, AAPV: general ambulatory palliative care, SAPV: specialized ambulatory palliative care	

About two-thirds of the palliative care patients (n=2,753) received only AAPV during the 12-month follow-up period and no further stationary palliative care or SAPV (Group A). One-third of the patients (n=1,424) received in addition to AAPV stationary palliative care and/ or SAPV (Group B) (Table 2). The median age in Group A was 82.0 (IQR: 75.0 – 88.0) years and in Group B 79.0 (IQR: 70.5 – 84.0) years. During the 12-

months follow-up, 57.9% patients from Group A and 89.2% from Group B died. The rate of oncological patients was lower in Group A (50.6%) than in Group B (80.5%). A Kaplan–Meier curve comparing the survival times of group A and B is shown in Fig. 1. The survival time curves differed between Group A and Group B, except in the first quartile of the survival distribution (survival probability from 1 to 0.75). The median survival time was significantly longer in Group A (137 days) than in Group B (47 days, log-rank test: $p < 0.0001$).

Table 2
Characteristics and survival times of the palliative care patients in Group A and B

	Group A	Group B
Number of palliative care patients	2,753	1,424
Age, years, median (IQR)	82.0 (75.0 – 88.0)	79.0 (70.5 – 84.0)
Female, n (%)	1,549 (56.3%)	731 (51.3%)
Dead, n (%)	1,595 (57.9%)	1,271 (89.3%)
- median number of survival days (95% CI)	137.0 (113.0, 172.0)	47.0 (42.0, 52.0)
Stationary or ambulatory diagnoses, n (%)	2,651 (96,3%)	1,411 (99,1%)
- oncological patients, n (%)	1,341 (50.6%)	1,136 (80.5%)
IQR: interquartile range (25 th quartile – 75 th quartile), CI: confidence interval, Group A: patients receiving only general ambulatory palliative care, Group B: patients receiving stationary or specialized ambulatory palliative care		

In Group A (n=2,753), one-third of the patients (n=986) received only one-day general ambulatory palliative care (Group A1), two-third more than one care day (Group A2) (Table. 3). The median age of both groups is 82.0 years. During the 12-month follow-up, 62.1% of patients from Group A1 and 55.6% from Group A2 died. The survival rate was lower in Group A1 (38%) than in Group A2 (44%). The rate of oncological patients was lower in Group A1 (46.8%) than in Group A2 (52.7%). A Kaplan–Meier curve comparing the survival times of the groups A1 and A2 is shown in Fig. 2. The survival curves differed between the two groups. The median survival time was significantly shorter in Group A1 (35 days) compared to Group A2 (217 days, log-rank test: $p < 0.0001$).

Table 3
 Characteristics and survival time of the palliative care patients in Group A1 and A2

	Group A1	Group A2
Number of palliative care patients	986	1,767
Age (years), median (IQR)	82.0 (75.0 – 88.0)	82.0 (75.0 – 88.0)
Female, n (%)	573 (58.1%)	976 (55.2%)
Dead, n (%)	612 (62.1%)	983 (55.6%)
- median number of survival days (95% CI)	35.0 (27.0, 56.0)	217.0 (167.0, 273.0)
Stationary or ambulatory diagnoses, n (%)	936 (94,9%)	1,715 (97,1%)
- oncologic patients, n (%)	438 (46.8%)	903 (52.7%)
Number of AAPV days, median (IQR)	1.0 (1.0 – 1.0)	3.0 (2.0 – 5.0)
IQR: interquartile range (25 th quartile – 75 th quartile), CI: confidence interval, AAPV: general ambulatory palliative care, Group A1: patients receiving only general ambulatory palliative care, treatment = 1 day Group A2: patients receiving only general ambulatory palliative care, treatment > 1 day		

Disussion

In general, palliative care patients who received only AAPV (Group A) had a longer survival time than patients who received also stationary palliative care or SAPV (Group B). This may indicate that patients in Group A had less severe symptoms or a better medical condition. In contrast, patients in Group B may have had a worse medical condition that required a higher level of care with specialized palliative care. The patients in Group B more often had a diagnose of cancer and the survival rate after 12 months of follow-up was lower than the patients in Group A. In the Kaplan-Meier survival curves, difference between the two groups was statistically significant. The curves also reveal how many patients died shortly after starting palliative care. The survival time of patients who died soon after the beginning of palliative care did not differ between the two groups. About a quarter of the patients in both groups died within two weeks after starting palliative care. In other words, the patients received palliative care only shortly before their death. This could mean that palliative care started too late for some of these patients.

Palliative care aims to improve the quality of life of patients and their families through the prevention of and relief from suffering by means of early identification and impeccable assessment and treatment of pain and other physical, psychosocial and spiritual problems [1]. Palliative care offers patients support so that they can live as actively as possible with a decent quality of life until their death. Therefore, palliative

care should start as early as necessary rather than just shortly before death. Studies suggest that timely palliative care can improve the quality of life of patients with advanced stage disease [14–18]. Early referral to palliative care for patients can facilitate appropriate monitoring and treatment of symptoms, longitudinal psychosocial support, counselling, and a gradual transition of care [14–16]. Besides, early palliative care can provide further benefits to the health care system by ameliorating the caregiver distress and health care costs associated with aggressive end-of-life care [17, 18].

Primary care providers, such as GPs, provide most palliative care in Germany. GPs play a key role in determining the need for palliative care and requesting a palliative care consultation, as well as coordinating referrals to palliative care specialists. GPs play an important role in coordinating early palliative care measures within the primary care structure. Although many GPs consider palliative care an essential part of their work, knowledge of palliative care and the structures of specialized palliative care were limited among GPs due to a lack of qualifications and experience in palliative care [19–21]. The present data, however, do not provide any information on the quality of palliative care provided by GPs.

The present study showed that about two-thirds of palliative care patients received only general ambulatory palliative care provided by GPs and no stationary palliative care or SAPV services (Group A). One-third of them received only one day of AAPV. The survival time of these patients (Group A1) was shorter than that of patients receiving more than one day of AAPV (Group A2). In contrast to Group A2, in which half of the patients died within seven months of starting AAPV, half of the patients in Group A1 died already within one month. Moreover, one-third of the patients in Group A1 died within one week after their first palliative care measure. This indicates a rather late start of palliative care for this subgroup of patients who received only AAPV. However, during the study period, a large proportion of patients in Group A1 survived after starting palliative care and received no further palliative care. This may be due either to the fact that no further palliative care was required for the patients or that the patients' initial assessment as palliative care patients by GPs was inadequate. It is a major challenge for GPs to ensure the assessment of patients who need AAPV or are to be referred to SAPV.

In one federal state in Germany (North Rhine-Westphalia), this problem is addressed by an innovative design of palliative care, whereby the basic concept is consciously designed to integrate AAPV and SAPV structures in one contract. Palliative care is based on cooperation between palliative physicians and GPs. Palliative physicians and coordinators are organized in this region at a regional level in palliative medicine consultation services. The coordinators of these services organize the cooperation between GPs, clinics, nursing homes as well as other facilities and the palliative physicians [22, 23]. Furthermore, since 2017, a new reimbursement code for physicians "specially qualified and coordinated palliative care" was introduced in Germany. The new reimbursement code is intended to facilitate transitions between curative treatment, AAPV and SAPV [24].

It should be taken into account that the claims data do not provide any information on palliative care provided by ambulatory nursing services, which probably also make an important contribution to the

provision of general ambulatory palliative care. However, little is known about the nature and extent of palliative care delivered by nursing services. Further research on this issue is needed.

Strengths and limitations

A strength of the study lies in the health insurance data, which includes both stationary and ambulatory data. This data allow to study the course of patients through different sectors of the health care system. However, a limitation of claims data is that they were collected for reimbursement purposes and may not fully and accurately reflect the individual health situation of the patients. Further limitations are that the patient's home situation is not reflected and the need for palliative care, especially AAPV, cannot be determined. Although a large part of the population in the study region is insured by AOK-Nordost, the results of the analysis may not fully extent to the entire population of palliative care patients.

Conclusion

The longer survival time of patients with AAPV may be an indication that this group had less advanced disease with less severe symptoms and that the kind of palliative care was probably appropriate. However, subgroups of patients received their first palliative treatment shortly before they died or did not receive any further palliative care after starting palliative care. Palliative care should start as early as necessary and continue until the end of life to improve the quality of life of patients.

Declarations

Ethics approval and consent to participate

Not applicable. Patients were not directly involved in the study. The present study is based on retrospective analysis of pseudonymised health insurance claims data and therefore no formal ethics committee approval was needed [13].

Consent for publication

Not applicable.

Available of data and materials

The data that support the findings of this study are available from AOK-Nordost but restrictions apply to the availability of these data, which were used under license for the current study, and so are not publicly available. Data are however available from the authors upon reasonable request and with permission of AOK-Nordost.

Competing interests

The authors declare that they have no competing interests.

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Authors contribution

KM contributed to the research questions, the analysis of the data, interpretation of the findings and drafting of the manuscript. LR, WH and NvdB contributed to the research questions and to the interpretation of the results. All authors revised the content of the manuscript, and read and approved the final manuscript.

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Figures

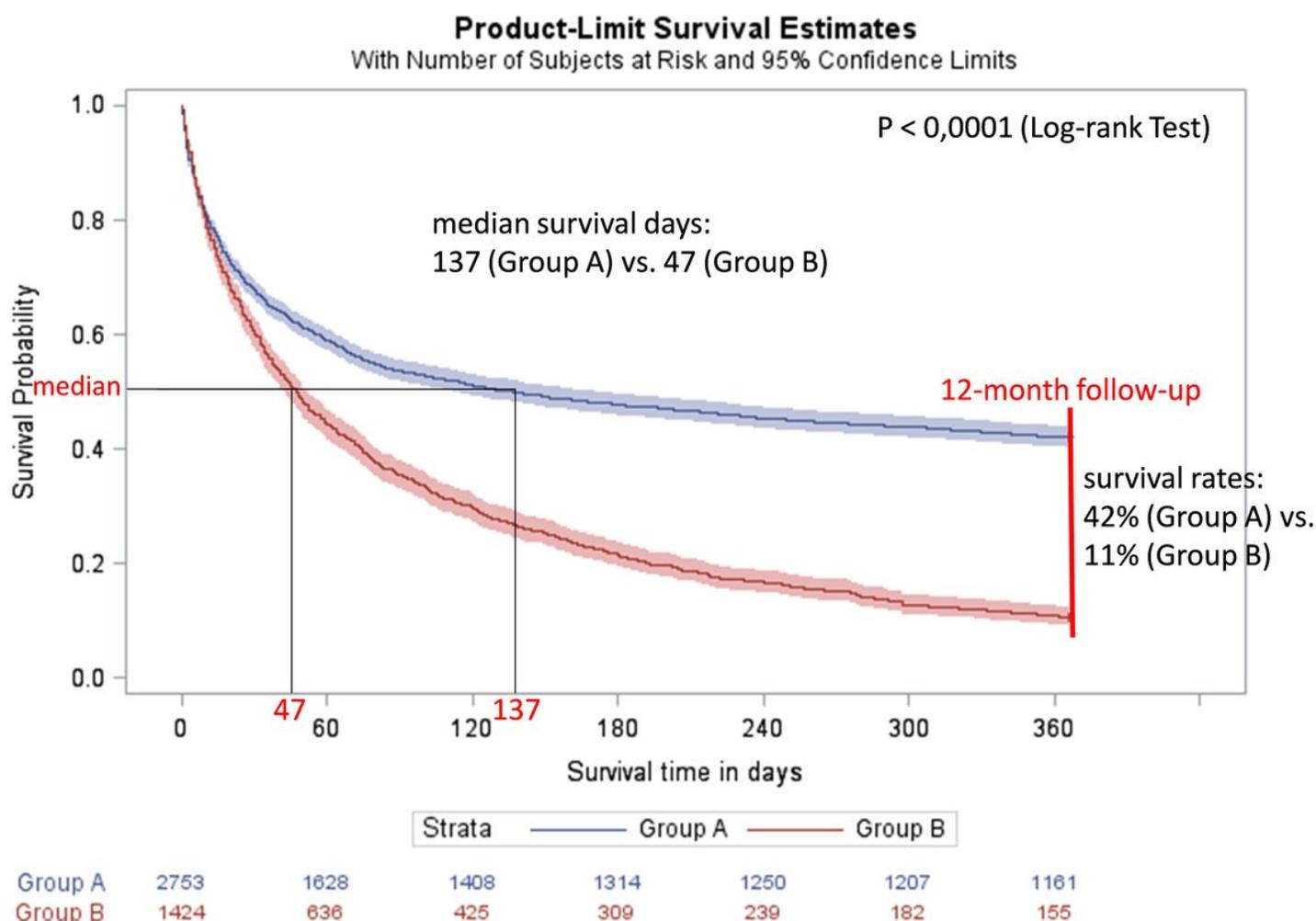
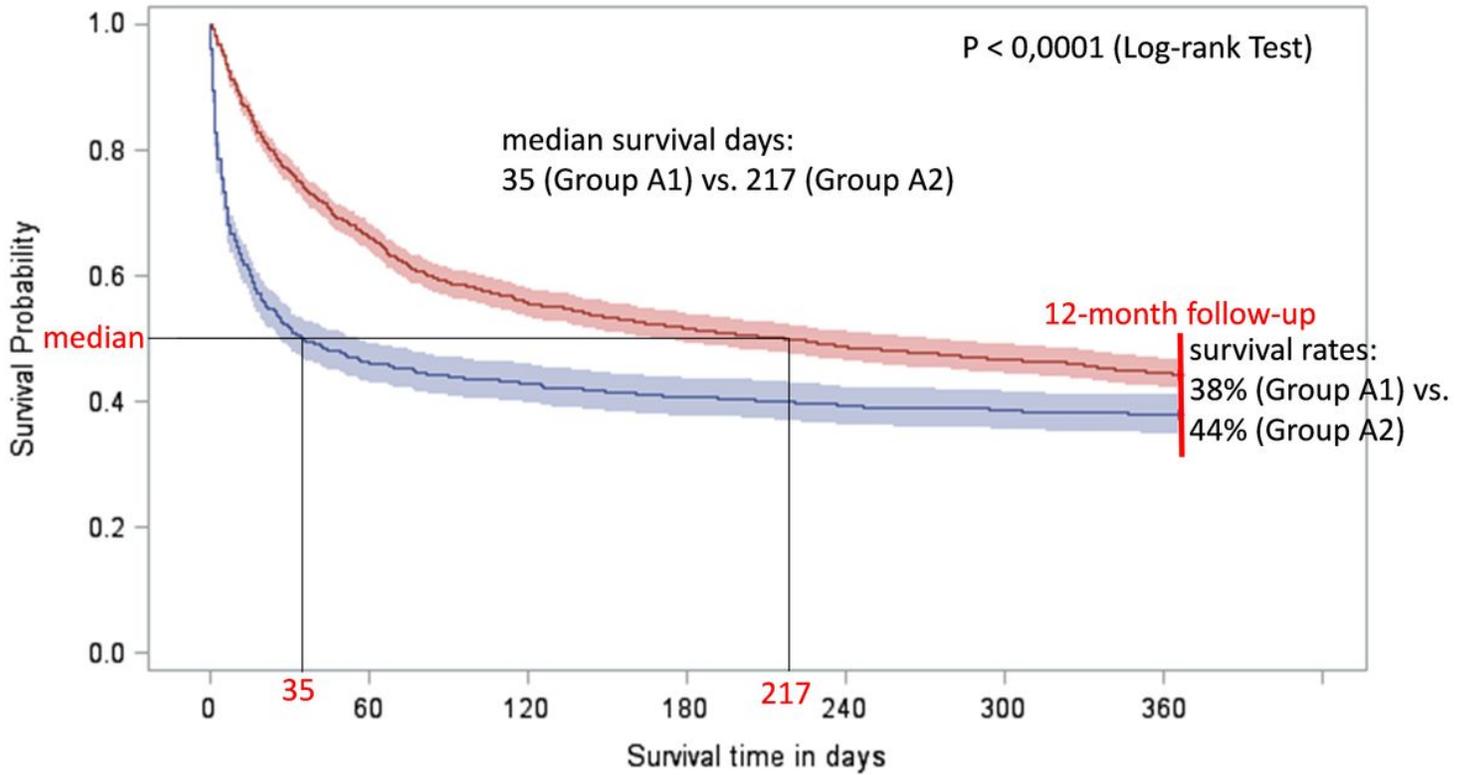


Figure 1

Kaplan-Meier Curve of palliative care patients (12-month follow-up): Group A vs. Group B
 Group A: patients who received only general ambulatory palliative care
 Group B: patients who received also stationary or specialized ambulatory palliative care

Product-Limit Survival Estimates

With Number of Subjects at Risk and 95% Confidence Limits



Strata — Group A1 — Group A2

Group A1	986	456	423	401	387	380	374
Group A2	1767	1172	985	913	863	827	787

Figure 2

Kaplan-Meier Curve of palliative care patients (12-month follow-up): Group A1 vs. Group A2
 Group A1: patients receiving only general ambulatory palliative care, treatment = 1 day
 Group A2: patients receiving only general ambulatory palliative care, treatment > 1 day